



## *Patient-centered Care*

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When I began in the primary care business very early on, I was privileged to have a planning grant from the Carnegie Fund and the Commonwealth Fund. Margaret Mahoney, who was then at the Carnegie Fund, would come up to Boston or I would come to New York. We would sit and ponder: What was this primary care thing? What were teams all about? We would plan and do things that were then considered crazy and now are terribly fashionable.

When we began trying to get doctors more involved in alcoholism and thinking about that, Margaret Mahoney was a stimulus. And Margaret now, with another extraordinary partner, Harvey Picker, one of the most remarkable men I've come across, has enabled me to take part in an 8-year, intoxicating voyage.

Patient-centered care is an awful word. It is the best way of turning off health professionals. We should come up with a better term. No one has done it yet, however, so we are stuck with it. Everyone thinks they are patient centered, and everyone takes umbrage when one suggests that they aren't.

We have been trying to develop a program that improves quality of care by looking through the eyes of the patients, seeing what is going on out there, seeing what is around the country and around the world that may improve care. What do I mean by all of this?

We have a special responsibility to build on the work of those early people who said, "We should see what happens to people when we do things to them." Codman was thrown out of Massachusetts General Hospital because he was a surgeon who dared say, "I think I ought to find out what happens to my patients after they leave the hospital." He was taken off the list by his col-

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leagues, to whom that was a heretical notion. Other people have said for quite a long time, "Learn from your patients," "Listen to your patients," "Hear them, and do something about it." That's the tradition in which we're trying to keep moving.

Consider my uncle. He is 91, quite a character, and he lives in England. He is German born, and he doesn't know what American health care is about, and he certainly doesn't know what his young Tom is about. He is an art dealer, not a health professional. So I keep trying to explain what I am doing, and he finally said, "I think what you're about is the democratization of health care." That is as well said as anything I've heard; that is what I think we are about in this mission.

The first thing we did was to ask patients, 'what have you experienced when you're sick?' Not, 'did you like it?' Not, 'was the doctor any good?' Instead, we asked, 'what did she or he do to you?' 'What happened to you when you were in the hospital?' 'What happened to you when you were in the doctor's office?' We have now done survey studies in this country, in Canada, in Great Britain, and in Germany. We are learning what patients experience, and the news is not all good.

For example: One in eight patients in this country, when they were surveyed after hospitalization, felt they had too little say in their treatment. One in three said that the doctor spent less than 5 minutes explaining what they could do when they left the hospital. One in four were not told when they could expect to resume what they usually did after they left the hospital. One in five were not told how they would feel after surgery. One in ten said no one explained the results of their surgery in a way that they could understand.

One in eight said there was no single doctor in charge. One in four women who had a C-section said that a doctor had not discussed that possibility with them beforehand. And one in four women who had given birth recently said the doctor had not discussed different options for pain management in and around delivery.

When you turn to office practice, one in four said the results of

their tests were not explained completely. One in five said their main reason for the visit was not addressed satisfactorily. And one in five in a primary care practice reported that they had not been as involved in decisions as much as they wanted to be.

All of us have things to work on. Our survey findings offer a strong contrast to global "satisfaction" measures that invariably suggest that everything is fine. We learn far more by asking what actually happened to people, rather than by seeking global, general responses that do not help us as physicians.

What have we done in response to our findings? We have brought together groups of hospitals, both public and private, to use patient-generated data to identify problems they have and then to fix what is broken. We have done the same thing in community health centers and HMOs. We now have young scholars working around the country. The third group of Picker/Commonwealth scholars has been selected, and we have now 15 exciting young academicians doing research that focuses on what patients perceive and what they experience.

We have also undertaken an interesting experiment: we have now established our own institute. The Picker Institute is alive and well. It is a not-for-profit organization, funded initially by the Commonwealth Fund and Boston's Beth Israel Hospital. It already has 20 people who work hard, organizing surveys of people all over this country and other countries, and offering educational programs.

We had our first annual conference 6 months after our inception and, to our excitement and astonishment, 525 people came to Boston to spend 3 intensive days with us, learning about what others are doing in this area, learning to draw on patient perceptions. We write books, we make movies, we serve as a switchboard and as a referral network so that people do not have to reinvent some very fascinating wheels that improve quality of care in institutions most health care practitioners have never heard about. We have a wonderful time as we move forward in a spirit of inquiry and research, drawing on patients' perceptions and learning from them.

Our ultimate goal is to invite patients to work with us in redesigning what we do not do well. I have a sense that, in the future, work teams will have patients on them. The governance of the units in our academic health centers, doctors' offices, or community health centers will have patient representation in ways we never thought possible in the past.

We find that doctors are a problem, and we're designing ways to draw them into this. We think we can do it. Doctors are driven by data; they are energized when they cannot answer questions easily. They like to solve problems. They're very smart, often too smart for what they do. We put them to work on some of these problems. We join them with their patients. Doctors may not want to listen to policy makers, administrators, or even their peers, but they will listen to their patients.

We think that patient reports make sense. They have face validity that sometimes resonates beyond some of our technical measures of quality, and we suspect that when doctors hear that their patients encounter problems, they will try to change delivery systems in ways that would not be considered otherwise.

Patients, therefore, are a wonderful lever for change. We suspect that there will be a day when you'll hear a lot about what patients say about this versus that, and that their words will probably have at least as much impact on the report cards as many other things you've heard about.

And finally, the patient's voice is the next step. I met a 65-year-old Jewish immigrant from the Soviet Union—he made sure that I didn't call him a Russian. He took a proper history from me today as I was driving here in his taxi, and ascertained that he was safe because I too am Jewish and could discuss things with him. He found out that I was a doctor, and he said, "You know, Doc,"—he didn't say it quite this way because he spoke in broken Russian, but he said something like this:

The trouble with you guys is, you don't listen to us. You don't hear what we have to say. We see things that you do that you just don't understand. You've got to put us in a

place where we can be heard, and we'll be fine about this health system. This is the greatest country in the world. I'm furious at the other people who came over with me and aren't grateful for being in America. But you doctors, you people in the health world, you don't listen. You've got to listen, and then we'll make a difference.

That is what the Picker/Commonwealth trip has been about. That is what the Picker Institute now is about. I commend it to you. We are having a wonderful time, and I hope you will join us in some of our efforts.